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Health-related quality of life in people with aphasia: Implications for fluency disorders quality of life research

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Abstract

It is becoming increasingly important that clinicians measure the health-related quality of life (HRQOL) of adults with communication disorders in order to monitor clients' progress and outcomes. This study reports on the impact of post-stroke aphasia on 30 Australian older adults' HRQOL. It also comments on the ability of the SF-36 Health Survey to measure HRQOL in this population, specifically whether the SF-36 is sensitive to the three determinants of post-stroke HRQOL – emotional, physical and social functioning deficits. Comparisons with other data are made to assist interpretation of the SF-36 scores: firstly with 75 older adults with no history of neurological conditions; and secondly with data from the 1995 National Health Survey data. The main findings are: (1) older adults with post-stroke aphasia have *similar* HRQOL to their peers, with two exceptions: they have significantly lower scores on the Role emotional and Mental health subscales than their peers; and (2) aphasic adults with depressive mood have significantly worse HRQOL than aphasic adults without depressive mood, with two exceptions: they have statistically similar scores on the Role emotional and Body pain subscales. Thus, the impact of aphasia on QOL is limited to the domains of emotional and mental health functioning. A different picture emerges for aphasic participants with depressive mood. Using the SF-36 as a measure of HRQOL with aphasic adults may not be advisable as it only identifies the impact of aphasia as depression. Implications of these findings for fluency disorders are briefly discussed.

Keywords: Aphasia; Quality of life; SF-36; Stuttering; Depression

1. Introduction

Aphasia is an acquired disorder of language that affects an individual's comprehension and expression across the range of modes of communication (listening, reading, speaking, writing, gesture, drawing, and calculation). It has a wide-ranging impact on the lives of those impaired

and their families, affecting employment, socialisation, and roles irrespective of how severe the linguistic impairment. Adults with aphasia and their relatives report numerous negative consequences of aphasia: changes in communication situations, changes in interpersonal relationships, difficulty controlling emotions, physical dependency, loss of autonomy, restricted activities, fewer social contacts, loneliness, changed social life, stigmatisation, and negative feelings of irritation, stress, annoyance, and anxiety (Le Dorze & Brassard, 1995; Zemva, 1999). Individuals with aphasia have reported a range of emotional responses, including fear, anxiety, bewilderment, despair, fury, amusement, frustration, isolation, shock, embarrassment, and depression, and as time goes by, resignation or increasing confidence (Parr, Byng, & Gilpin, with Ireland, 1997). The consequences of aphasia are in several ways similar to the consequences of stuttering on the individual. Stuttering impacts on individual's speaking (fluency, naturalness, rate) and the ability to communicate generally in everyday life; can cause embarrassment, frustration, shame and avoidance behaviours; and often has an impact on individuals' employment, social lives, sense of self, and relationships (Yaruss & Quesal, 2004). Whilst stuttering is experienced initially in childhood, aphasia is a chronic condition acquired later in adulthood, and depends on the neurological areas damaged during the stroke, and has variable presentation within the individual, that is, those with aphasia report good days and bad days. In aphasiology, there is a range of approaches to assessment and treatment that generally aim to reduce the effects of the impairment and improve the person's language functioning and communication ability. Many approaches are directed at the aphasic adult, however in the last decade there is an increasing evidence base for conversation partner approaches and social approaches to life participation (Simmons-Mackie, Conklin, & Kagan, 2008), and concurrent enquiry into quality of life with aphasia (Cruice, Worrall, Hickson & Murison, 2003; Hilari, Wiggins, Roy, Byng, & Smith, 2003) using health-related quality of life (HRQOL) and wellbeing

tools. Although the emotional and psychological sequelae of aphasia and stuttering have been rather equally well researched since the 1970s, the line of enquiry into quality of life has been better investigated in the field of aphasiology. As we move forward as a profession in quality of life research, it is helpful to consider the evidence base in other clinical areas, and derive what lessons might be appropriate for fluency disorders.

The Short Form 36 Health Survey (SF-36: Ware & Sherbourne, 1992; Ware, Snow, & Kosinski, 1993) has been used across all ages of the adult lifespan to measure population HRQOL; in clinical populations spanning disease, illness and disability; and also in the caregivers or family members of those with a health condition. Research questions using the SF-36 are generally focused on clinical populations, using it as an outcome measure of perceived health and/or HRQOL, often amongst a range of other measures of functioning. These studies explore differences amongst diagnostic groups (e.g., Chia et al., 2006) or seek to compare effects of different treatments or service delivery options (e.g., Stark & Hickson, 2004). The SF-36 is now the most frequently used generic HRQOL measure in stroke research (Geyh, Cieza, Kollertis, Grimby, & Stucki, 2007), and is often used to measure HRQOL at different times post stroke (Hagen, Bugge, & Alexander, 2003) and a measure of improvement post rehabilitation (Madden, Hopman, Bagg, Verner, & O'Callaghan, 2006). Concurrently, there is conceptual examination of the constructs of the SF-36, amongst other HRQOL and outcome measures, to clarify what exactly is being measured (Geyh et al., 2007; Salter, Moses, Foley, & Teasell, 2008; Schepers, Ketelaar, van de Port, Visser-Meily, & Lindeman, 2007). This paper contributes to the evidence base of the SF-36 by reporting the HRQOL of a clinical population, namely people with aphasia after stroke, but also critiques the measurement of HRQOL and the use of the SF-36 in this communication disordered group, and the issues in reporting such data. It is anticipated that

researchers in the area of fluency disorders will profit by lessons learned when studying the HRQOL of people with aphasia.

1.1 Post-stroke HRQOL

The three most common factors or determinants of quality of life (QOL) after a stroke are depression, physical functioning/ disability, and social functioning (Bays, 2001; Jaracz, Jaracz, Kozubski, & Rybakowski, 2002; Jonkman, de Weerd, & Vrijens, 1998; Kauhanen, Korpelainen, Hiltunen, Nieminen, Sotaniemi, & Myllylä, 2000; Kim, Warren, Madill, & Hadley, 1999; Williams, Weinberger, Harris, & Biller, 1999). Many studies cite depression as the most important predictor of HRQOL (Jonkman et al., 1998; Kauhanen et al., 2000; Naess, Waje-Andreassen, Thomassen, Nyland, & Myhr, 2006). Depression and physical functioning are both early and long-term indicators of post-stroke QOL (Naess et al., 2006). While many post-stroke QOL studies in the 1980s and 1990s included measures of social functioning (Bays, 2001; King, 1996; Labi et al., 1980; Niemi et al., 1988), these days social indices are less frequently reported, and current studies favour measures of physical ability, anxiety and depression, cognitive impairment and activities of daily living.

1.2 Post-stroke HRQOL with aphasia

The evidence base in HRQOL of aphasic adults is limited because aphasic participants are under-represented in published studies. Most large-scale stroke studies have excluded aphasic participants because research investigators have not been trained to support the communication needs of aphasic participants during data collection. Hence, it is within the much smaller field of speech pathology where HRQOL with aphasia has been investigated. The studies show that: (1) depression, functional communication ability, involvement in home and outdoor activities, and

number of comorbid conditions predict HRQOL (Cruice et al., 2003; Hilari et al., 2003); (2) physical or physiological health predicts social participation (Cruice et al., 2003); (3) language functioning, independence, social relationships, and the environment predict general QOL and psychological wellbeing (Cruice et al., 2003; Ross & Wertz, 2003); and (4) qualitatively, QOL is influenced by one's activities, verbal communication, people, body functioning, stroke, mobility, positive personal outlook, in/dependence, home and health (Cruice, Hill, Worrall, & Hickson, 2009).

Speech pathology researchers have successfully used a number of tools, including the SF-36 Health Survey, to measure aphasic adults' QOL. Cruice et al. (2003) found that scores on the SF-36 subscales General health, Social functioning, Physical functioning, and Role Physical were predicted by participants' scores on emotional health, near vision, functional communication ability, and social activities measures. Thus, emotional health is a consistent strong predictor of HRQOL, general physiological health influences social functioning and social activities, and functional communication skills and social functioning are related. Thus, the three determinants of HRQOL after stroke – depression, physical and social functioning - are relevant to HRQOL with aphasia. Communication, activities, and physiological health also need to be considered in HRQOL with aphasia. Although communication and activities are not represented *per se* in the SF-36 conceptual framework, it is hypothesized that they would manifest in the emotional (Role emotional, Mental health) and social functioning subscales of the SF-36. Physiological health is not represented well in the SF-36 either, but hypothesized to manifest in the physical functioning subscale.

Although the existing evidence base regarding HRQOL post-stroke with aphasia indicates a range of predictors or determinants, there is limited research into the impact stroke and aphasia has on one's HRQOL. One way of exploring this is through comparison with a non disorderd population, which we pursue in this paper. Thus, we compared the HRQOL as measured by the SF-36 of a group of 30 older persons with post-stroke aphasia, with a group of 75 older persons with no neurological history. A further comparison and interpretation of the data is made using two published SF-36 data sets (clinical stroke group and normal population group) from the Australian Bureau of Statistics (ABS) 1995 National Health Survey data. Using published data to assist interpretation carries various cautions, as will be highlighted later in this paper. The sequentially investigated research questions were:

(1) Do older people with post-stroke aphasia have significantly worse HRQOL compared with older people with no neurological history?

(2) How does depressive mood impact on HRQOL in post-stroke aphasia?

(3) Is there any difference between the HRQOL of people with post-stroke aphasia and people with no neurological history, when depressive mood is removed from the equation?

2. Methods

2.1 Participants

One hundred and five participants took part in this study, 30 with aphasia post-stroke (16 females, 14 males) and 75 without stroke and aphasia (47 females, 28 males). For ease of reading, these two groups will be referred to as the aphasic and non-aphasic groups. All participants spoke English as their first language, lived independently in the community, and were 60 years or older (Note that two aphasic participants were under 60 years of age but were included as participants meeting the selection criteria were scarce). Participants were drawn from

the same geographical area, in metropolitan Brisbane and the surrounding area up to 150 kilometres. The aphasic group met the following criteria: had no concomitant neurological disease, confirmed by hospital records, clinical observation, and self-report at interview; were greater than 10 months post-stroke; demonstrated aphasia at time of stroke and reported ongoing aphasic difficulties; had a reliable yes/no response (no less than 16/20 on *Western Aphasia Battery* (WAB) Yes/No Questions, Kertesz, 1982); had moderate comprehension ability at time of interviewing (no less than 5/10 on WAB Comprehension subtest); and had normal to moderate mobility (persons requiring a wheelchair were excluded). Non-aphasic participants were excluded if they reported a history of cerebrovascular or neurological disease.

Information regarding months post onset for the aphasic group, and age and education for both groups is reported in Tables 1 and 2. Education was calculated in terms of years spent in schooling, higher education and training. Although the aphasic group had a range of language impairment (mild to moderate-severe) indicated by the WAB Aphasia Quotient scores (Table 1), the majority of scores fell between 60 and 89, indicating a bias towards mild to moderate impairment. As functional communication skills are more predictive of HRQOL than language impairment (Cruice et al., 2003), average scores for aphasic participants on the Communication Activities of Daily Living – Second Edition (CADL-2: Holland et al., 1999) are also reported in Table 1.

Insert Table 1 about here

2.2 Materials and Procedures

Ethical approval for this study was gained from the University of Queensland and the ethics committees of the three hospitals from which aphasic participants were recruited. Aphasic participants' understanding and consent to participate in the study was supported using pictorially supplemented versions of the information sheet and consent form, using information accessibility guidelines. Participants reported in this paper were part of a larger study investigating relationships amongst variables of communication and QOL (see Cruice et al., 2003; Cruice, Worrall, & Hickson, 2005). This study employed a test battery of 15 measures of language, hearing, vision, communicative abilities and activities, social networks and activities, HRQOL, wellbeing, and emotional health or depression. Assessments were chosen on the basis of greatest applicability to both participant groups, psychometric value, and minimal respondent burden. Length of assessment was especially important considering the broad scope of assessment, and where possible, abbreviated versions of assessment tools were used.

The Short Form–36 Health Survey (SF-36: Ware & Sherbourne, 1992; Ware et al., 1993) was used to measure HRQOL in all participants. The SF-36 assesses eight health concepts: (1) limitations in physical activities because of health problems; (2) limitations in social activities because of physical or emotional problems; (3) limitations in usual role activities because of physical health problems; (4) bodily pain; (5) general mental health (psychological distress and well-being); (6) limitations in usual role activities because of emotional problems; (7) vitality (energy and fatigue); and (8) general health perceptions. It yields eight subscale scores across physical and mental health. The Australian validated version of the SF-36 was used (IQOLA SF-36 Standard Australian Version 1.0), which was available at the time of data collection in 1999-2001. Raw scores on the SF-36 Health Survey were reversed (if required), summed, re-calibrated

and transformed according to the standard guidelines, yielding 8 raw subscale scores and 8 transformed subscale scores. For all of the 8 SF-36 subscales, a scale of 0-100 is used, wherein higher scores indicate a better state of HRQOL. Three scales are considered bipolar scales, that is, General Health, Vitality, and Mental Health. This means that a score of 50 equals no limitations or disability, and 100 indicates positive state of wellbeing. In the remaining five subscales, a score of 100 indicates no limitations or disabilities.

The SF-36 contains yes/no questions, true/false questions and frequency questions, and the average time for self-completion is reported as 10 minutes (Bell & Kahn, 1996; Hayes et al., 1995). In the current study, length of interviewer-supported completion was recorded for 26 of the 30 aphasic participants, and averaged 23 minutes (SD = 6, range 14-35 mins) (Cruice, 2001). Interviewer-supported completion time for non-aphasic participants was 11 minutes (n = 49 of 75 participants recorded: SD = 4.4, range 3 to 30). Extensive psychometric evaluations of the SF-36 have previously been undertaken, and the Australian version of the questionnaire, which was used in this study, has demonstrated internal consistency, test-retest reliability, and construct validity (Sanson-Fisher & Perkins, 1998). There is some concern about the use of the SF-36 in stroke, for example, its ability to capture physical and/or social functioning post-stroke (Anderson, Laubscher, & Burns, 1996; Lai, Perera, Duncan, & Bode, 2003).

The 15-item version of the Geriatric Depression Scale (GDS: Sheikh & Yesavage, 1986) was used to measure depressive mood or emotional health in all participants. Participants answered ‘yes’ or ‘no’ to 15 questions depending on how they had felt over the past week. Questions are counterbalanced, alternating positive and negative responses, and one point is counted for each depressive answer. A score of 0-4 indicates normal mood or emotional health status, 5-9 indicates

mild depression, and 10-15 indicates moderate to severe depression. The GDS has good reliability, validity, sensitivity and specificity for older people (McDowell & Newell, 1996). The GDS, in various versions, has been used in stroke (Appelros & Viitanen, 2004; Jönsson, Lindgren, Hallström, Norrving, & Lindgren, 2005; Leeds, Meara & Hobson, 2004), and performs well in terms of internal consistency, sensitivity, and predictive value (Agrell & Dehlin, 1989).

The first author assessed each participant in his/her own home, thereby eliminating mobility and transport problems, which are prominent barriers for participation of both groups. As the SF-36 is a complex and challenging scale for language-impaired participants (Cruice, Hirsch, Worrall, Holland, & Hickson, 2000), a cuing or prompting procedure for the SF-36 was developed. The cues were originally generated for aphasic participants but were also applicable for non-aphasic participants who found items difficult to understand. The first cue was an exact repetition of the question spoken more slowly and using chunked information. The second cue was the question rephrased to reduce or simplify the question. The third cue was one that made the question relevant for the person (based on previous shared knowledge between researcher and participant or the immediate physical and social environment). The cuing procedure has not been tested for reliability. Aphasic participant characteristics were statistically associated with the number of cues given during SF-36 administration. Participants with lower WAB AQ scores and Comprehension subtest scores required more cues on the SF-36 (Cruice, 2001).

2.3 Analysis and interpretation

Independent t-tests were used through the statistical analysis to compare aphasic and non-aphasic data. Because the groups differed in size, Levene's test for homogeneity of variance was used. Variances are reported as equal or significantly different in the tables. To investigate depressive

mood *within* the aphasic sample, the range scores for the GDS were used to identify those who had no depressive symptoms (0-4) and those who did, creating a binomial variable. Nonparametric independent sample comparisons (Mann Whitney U test yielding Z scores) were used for subgroup comparison of normal aphasic and depressed aphasic participants. No statistical comparison is possible with the ABS data sets for stroke and no stroke/population data, and instead, the reader is encouraged to visually compare the means for SF-36 subscales alongside the data collected in the current study (standard error of the means were reported, but standard deviations and ranges were not reported). It is important to note that sample sizes are small compared with typical large-scale stroke QOL studies, and do not have the statistical power seen in some of these studies.

3. Results

3.1 Research Question 1: Comparison of aphasic and non-aphasic groups' HRQOL

Table 2 presents the aphasic and non-aphasic data on the SF-36 subscales. Aphasic participants have significantly lower Role emotional and Mental health HRQOL scores compared to non-aphasic participants. Role emotional is defined as "the effects of emotional problems on a person's performance of their work or other daily activities; i.e. whether limited in the kinds of work or other activities they were able to do, or reduced the time spent on those activities, or had difficulty in performing those activities due to emotional problems" (ABS, 1995, p4). Mental health describes "the amount of time a person experienced feelings of nervousness, anxiety, depression and happiness" (ABS, 1995, p4). Physical functioning HRQOL approached significance. Other differences between the samples were: aphasic participants were significantly younger by 3-4 years, had fewer years of education (approx. 2 years), and had significantly higher GDS scores indicating more depressive symptoms.

Insert Table 2 about here

3.2 Research Question 2: The impact of depressive mood on HRQOL post-stroke with aphasia

In the aphasic group, the majority (21) had normal emotional health on the GDS, six participants had mild depressive problems (5 women, 1 man), and the remaining three scored as moderately to severely depressed (1 woman, 2 men). One mechanism for considering depression in statistical calculations is through regression statistics, as already available in Cruice et al. (2003, 2005). The alternative is to divide the participant sample into subgroups, in this case, a subgroup of aphasic normal mood scores (n = 21) and a subgroup of aphasic depressive mood scores, ranging from mild to moderately severe depressive symptoms (n = 9). In the non-aphasic group, only 2 of 75

participants scored outside the normal range, making any kind of within-sample comparison redundant. Thus, a further comparison was made between the two aphasic subgroups. Table 3 presents demographic information and SF-36 subscale scores for non-depressed aphasic participants (n=21, shaded rows) and depressed aphasic participants (n=9). We acknowledge that the sample sizes of subgroups are low, and larger numbers are needed for robust findings.

Insert Table 3 about here

Non-depressed aphasic participants had significantly higher Physical functioning, Role physical, General health, Vitality, Social functioning, and Mental health HRQOL scores than depressed aphasic participants. Non-depressed aphasic participants were significantly younger, and obviously, had significantly lower GDS (i.e. better) scores than their depressed aphasic peers. Because of the significant differences in HRQOL between the subgroups, other variables that may contribute to differences between the samples were investigated. Table 4 outlines the statistical comparisons made for language functioning, functional communication ability, and social life participation. None of these comparisons was statistically significant. Further analysis using additional impairment variables from the larger study (Cruice et al., 2003) including naming, distance vision, near vision, and hearing was conducted, and also revealed no significant statistical differences between aphasic subgroups (not reported in Table 4). Thus, there were no significant differences between the aphasic subgroups with the exception of depression and age that accounted for the markedly worse HRQOL post-stroke with aphasia *and* depression.

Insert Table 4 about here

3.3 Research Question 3: Comparison of aphasic and non-aphasic with depressive removed from the equation

Because depressed aphasic participants had significantly worse HRQOL than non-depressed aphasic participants, it begs the question of whether it is depression alone that is responsible for the HRQOL differences between clinical and normal ageing populations. That is, how similar are non-depressed aphasic participants to non-aphasic participants. Table 5 compares the SF-36 subscales scores for 21 non-depressed aphasic participants and 73 non-depressed non-aphasic participants (2 with cut-off depression scores removed from sample). Significant results only are reported. Aphasic participants had significantly better General health HRQOL, were significantly younger, and interestingly, were still more depressed (i.e. higher GDS scores indicating more depressive symptoms) than non-aphasic participants. The subscale General health "combines self-assessed health status with indicators of current expectations and perceptions of health relative to the health of others" (ABS, 1995, p4), and is based on responses to 5 questions. Thus, with the exception of General health, non-depressed aphasic participants' HRQOL is not statistically different to that of their non-depressed non-aphasic peers.

Insert Table 5 about here

3.4 A final comparison for interpretation of SF-36 scores

Population data on the SF-36 is available through the Australian Bureau of Statistics (ABS) National Health Survey (NHS): SF-36 Population Norms (ABS Catalogue No. 4399.0 or available online at http://www.ausstats.abs.gov.au/ausstats/free.nsf/0/C32B970BCC3E56E0CA257225000495DE/$File/43640_1995.pdf). The SF-36 was administered to approximately 18,800 adult residents

throughout Australia, during the period of February 1995 to January 1996, approximately four years before the current study's data was collected. Stroke (including the after effects of) was one of the serious physical conditions recorded in the NHS. The population norms provide data on 110 stroke survivors, aged 55years and over, and compares these with 4, 459 persons who have not had a stroke, who are assumed to also be 55years and over. More detailed information, such as time post stroke and depression in both groups, is not available in the online document. Table 6 contains 6 columns of data for final comparison and interpretation of SF-36 subscales. It includes descriptives for the 8 transformed scores for the aphasic group (N = 30), non-depressed aphasic subgroup (n = 21), depressed aphasic subgroup (n = 9), ABS 1995 stroke group (N = 110), non-aphasic group (N = 75), and ABS 1995 'no stroke' group (N = 4,459).

Insert Table 6 about here

Based on analyses carried out above: (1) aphasic and non-aphasic participants differed on the three SF-36 subscales of Role emotional, Mental health, and General health; and (2) depressed and non-depressed aphasic participants differed on six SF-36 subscales (not Body pain and Role emotional). From visual comparison of means in Table 6: (1) depressed aphasic participants look similar to ABS stroke data on all subscales with the exception of Role emotional; (2) aphasic participants (N = 30) and the non-depressed aphasic participants (n = 21) look different and higher to ABS stroke data on all subscales; (3) aphasic participants look similar to ABS 'no stroke' or population data on Vitality, Social functioning and Mental health subscales; and (4) aphasic participants look different to ABS 'no stroke' or population data on Body pain and General health (higher), and Physical functioning, Role physical, and Role emotional (lower).

4. Discussion

4.1 The impact of post-stroke aphasia on HRQOL in older adults

Older adults with post-stroke aphasia had significantly worse emotional and mental HRQOL compared to their non-disordered peers. They reported a greater influence of emotional problems on their daily activities or work, and more time experiencing feelings of nervousness, anxiety, depression and lowered happiness, in the four-week timeframe considered by the SF-36. They also had a lower average Role emotional subscale score compared to the Australian population data. These findings confirm previous research that emotional functioning is a significant consideration in aphasia and central to quality of life (Cruice et al., 2003; Hilari et al., 2003; Le Dorze & Brassard, 1995; Zemva, 1999). They also demonstrate that the SF-36 is a sensitive measure detecting emotional deficits in this clinical population. This finding concurs with recent research into other communication disorders wherein Craig and colleagues (2009) found that stuttering had a negative impact on the emotional and mental HRQOL of 200 adults who stuttered compared with 200 adults who didn't stutter. Unlike Craig et al. (2009), this study found that a communication disorder had no significant negative impact on aphasic adults' social functioning. Furthermore, any post-stroke physical difficulties experienced by the aphasic adults were not detected by the SF-36. This suggests that post-stroke aphasia has a limited impact on HRQOL or that the SF-36 is not an appropriate tool for people with aphasia.

4.2 The impact of depressive mood on post-stroke HRQOL with aphasia

Abnormal levels of depressive symptoms substantially impacted on the HRQOL results of this study. Firstly, removing depressed aphasic participants from the analyses neutralised the previously significant finding of emotional and mental health differences between aphasic and non-aphasic adults. Furthermore, it showed aphasic adults to have even better HRQOL than their

peers, in the area of general health perceptions. If statistics alone are considered, then this study shows a positive finding for aphasic adults who experience no detrimental impact on their HRQOL as a result of their communication disorder. However, a vast body of research published on the negative life consequences of aphasia would lead us to think otherwise. The most pronounced effect of abnormal depressive symptoms is in the aphasic subgroup comparisons. Here, depressed aphasic participants had significantly worse HRQOL across most areas, excluding Role emotional and Body pain subscales. None of the differences could be accounted for by linguistic impairment or communication ability severity, which is typically assumed to be the causes of lower HRQOL. Aside from depression, age was the only other consideration that accounted for markedly worse HRQOL with post-stroke aphasia. It is not known whether depression and these HRQOL deficits co-occur, are causally related, or are a result of self-reporting bias wherein depressed individuals may rate self-report scales lower. However, it does clearly indicate that the SF-36 detects depressive mood, physical and social functioning deficits post-stroke in depressed aphasic adults.

4.3 Issues in reporting and interpreting HRQOL data

Without some form of comparison, it is challenging to work out what the HRQOL SF-36 subscale data actually mean. The data presented in this paper clearly demonstrate that aphasic adults' HRQOL bears little resemblance to the ABS stroke data, which would be considered a reasonable comparison group for the current study. Using the latter as a basis for comparison, one could interpret that post-stroke aphasic adults do *not experience* stroke deficits and do not experience any detrimental effects from aphasia. Clearly these are misinformed judgments, but are easily made. Instead, it is the depressed aphasic adults who more closely resemble the ABS stroke data. Such differences are likely to be attributed to different levels of depression between

the samples, different times post-onset, and different degrees of communication impairment present in the stroke respondents who were interviewed. This study's findings are a clear reminder of the need to report HRQOL data within the context of depressive mood characteristics of the respondents.

4.4 Implications for clinical practice and research

People with aphasia reported significantly higher levels of depressive symptoms compared to their peers, regardless of whether they were in the normal bracket for the GDS scores (0-4) or the abnormal bracket (scores of 5 and above). Therefore, addressing how people with aphasia feel is essential in clinical assessment and intervention, as well as through referral to other professionals when appropriate. Clearly, emotional functioning is also relevant to the management of other adult communication disordered populations such as stuttering (Craig et al., 2009). The Geriatric Depression Scale (15 item version) appears clinically useful in identifying depressive symptomatology in older persons, and its yes/no response format is easily accessible for people with aphasia. Research is also needed to understand why such a large proportion of a small aphasic sample had such high levels of depressive mood post stroke. This is particularly concerning given that most were no longer in regular contact with speech pathology or stroke healthcare services. Services across the continuum of care need to routinely include screening for depression.

The SF-36 can be used to identify emotional and/or mental, physical and social functioning deficits in older adults with aphasia who have abnormal levels of depressive symptoms. In this study, this was approximately one third of the chronically aphasic, community-living population. For the majority of the aphasic population though, an alternative measure of HRQOL is needed,

especially to identify social functioning, which is of prime importance in aphasic QOL (Cruice et al., 2003). As the SF-36 contains only two items on social functioning, which are described in relation to limitations or interference of physical or emotional problems, it is unsurprising that the subscale does not differentiate aphasic from non-aphasic adults. HRQOL measures with a greater proportion of social functioning items are recommended. The review of HRQOL measures in stroke carried out by Salter and colleagues (2008) suggests that the Stroke-Adapted Sickness Impact Profile-30 (SA-SIP-30: Van Straten et al., 1997), the Stroke Impact Scale (SIS: Duncan et al., 1999), and the Stroke Specific Quality of Life Scale (SSQOL: Williams et al., 1999) contain a high number of social and role activities items. All three also have good coverage of physical functioning (Salter et al., 2008), with the latter two being more comprehensive. Geyh and colleagues (2007) also recommend the SIS and SSQOL for relevant content, as well as the Stroke and Aphasia Quality of Life Scale (SAQOL-39: Hilari et al., 2003). Most of these measures still need to be tested with large numbers of aphasic individuals with varying levels of communication ability to determine their suitability in this clinical population. The development of specific QOL measures for stuttering also remains a challenge and a goal for future research (Franic & Bothe, 2008).

Aside from the question of which measure is the most relevant to use with aphasic adults, there is a further question regarding the role of standardized HRQOL measures in speech pathology intervention in general (including those for fluency disorders). Used according to standardized administration guidelines, the SF-36 does not facilitate goal or therapy planning, and provides only the participant's perspective on his or her functioning in a range of health-related areas. It does not reflect personal importance or satisfaction, nor does it indicate the individual's goals, expectations, standards and concerns about his or her HRQOL. Respondents often have difficulty

making clear cut decisions about how to answer the questions, as the example below from Mallinson (2002, p16) illustrates. R represents the researcher, P represents the participant.

R: Can you walk half a mile?

P: Where's half a mile?

R: Say, down to the garden centre, maybe a little bit further than that.

P: I can walk down to the garden centre but there's no way I could get back because it's up-hill, and as soon as I, I can't walk up that hill so it depends which, if you're talking about on the flat, slowly, not talking or carrying anything…I can walk around the shopping precinct and round the supermarket because you're going slowly and you're stopping and looking at things and you're not talking to anybody.

R: What about 100 yards? Would you say you are very limited over 100 yards or just a little bit limited?

P: 100 yards on the flat, fine. 100 yards up a hill - I wouldn't tackle it (Mallinson, 2002, p16).

Recording the participant's reasoning however provides much useful information for contextualizing potential goals and intervention. Valuable information about someone's QOL can be learned through discussion using structured questions about current and future QOL (Cruice et al., 2009). Franic and Bothe (2008) after reviewing 10 stuttering specific instruments for HRQOL constructs also advocated open ended questions and conversations between the clinician and client.

A major limitation of this research is the sample size, and more research with much larger samples of participants is needed for robust findings and definite conclusions regarding both

HRQOL assessment in aphasia and the use of the SF-36 with this population. Studies in stuttering with samples of 200 adults (Craig et al., 2009) and studies in hearing impairment with samples of 2,431 to 2,688 (Chia et al., 2007; Dalton, Cruickshanks, Klein & Klein, 2003) show significant differences between communication disordered and normal populations, and significant differences amongst individuals with varying degrees of severity of impairment. Finally, the SF-36 is not the only measure of HRQOL, and other measures of HRQOL are more accessible for people with aphasia, namely the Dartmouth Coop Charts (Nelson et al., 1987) and the SAQOL-39 (Hilari, Byng et al., 2003), and have been used with success (Cruice et al., 2000; Cruice et al., 2003; Hilari et al., 2003).

Finally, some explicit reflection is needed on the expected relationship between impairment and HRQOL in communication disorders. Research in hearing impairment demonstrates a link between hearing severity and HRQOL (Chia et al., 2007; Dalton et al., 2003) and recent research shows a trend for adults with increasingly severe stuttering to have a higher risk of poor emotional functioning on the SF-36 (Craig et al., 2009). Thus we assume a link between impairment and HRQOL. However, within aphasia research to date, it is severity of functional communication not language impairment that has predicted HRQOL (Cruice et al., 2003; Hilari et al., 2003), and other variables such as physical functioning after stroke, have a significant impact on HRQOL (Cruice et al., 2009). Researchers whilst investigating the impact of communication disorders on HRQOL must also consider the individual's overall presentation and include other factors in HRQOL research.

Research in the field of fluency offers some interesting insights for aphasia clinicians and researchers. Fluency considers the reactions of others, much more than aphasia considers this

area, and there is recognition of the influence of internal and external factors. Adults who stutter experience their impairment to a great degree on how others respond to the stuttering. The reactions of others have been embedded in well-evidenced models of stuttering and questionnaires (Yaruss, 1998). There is also a long history of studying the individual's affective, behavioural and cognitive reactions to his or her own stuttering (Yaruss, 1998) and not simply measuring the severity of stuttered speech. This suggests a greater awareness in fluency of the personal and environmental factors of communication disorder. Following a similar direction in aphasia may facilitate aphasic adults to recognize the responsibilities of others in addressing communication disability and justify more speech pathology interventions aimed at improving the immediate and community communication environments and societal attitudes. Such interventions are likely to have broad ranging impacts across a range of adult communication disorders, and may collectively improve HRQOL of these persons.

5. Conclusion

The SF-36 distinguishes aphasic from non-disordered HRQOL on the basis of emotional functioning, but does not identify physical and social functioning deficits, the latter of which is core to the construct of post-stroke HRQOL with aphasia. However, the SF-36 is comprehensively sensitive for persons who have post-stroke aphasia *and* depressive mood. As the SF-36 is linguistically and cognitively challenging for respondents with impaired language skills, it is not the measure of choice for this clinical population although it may be relevant for other communication disordered groups. More research is needed with larger sample sizes and a broader range of age and comprehension skills of aphasic adults to make definite conclusions about post-stroke HRQOL with aphasia.

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Table 1

Time post onset, language and functional communication scores in aphasic participants, N = 30.

Variable	**Mean**	**Standard deviation**	**Minimum**	**Maximum**
Time post onset (months)	41.1	25.6	10	108
WAB AQ (Max = 100)	74.34	18.56	21.9	95.8*
WAB SponSpee (Max = 20)	15.03	4.16	4	20
WAB Comp (Max = 10)	8.49	1.3	6.05	10
WAB Rep (Max = 10)	6.92	2.87	0	10
WAB Naming (Max = 10)	6.74	2.41	0	9.5
CADL-2 (Max = 100)	73.4	16.72	31	95

* Four participants exceeded standard 93.8 WAB cut-off but were included as they demonstrated clear aphasic impairment difficulties

Table 2

Comparison of aphasic (N = 30) and non-aphasic (N = 75) participants' demographic data and SF-36 subscale scores.

Variable	**Mean A/ Non-A**	**Standard deviation A/ Non-A**	**Standard Error Mean A/ Non-A**	**Range A/ Non-A**	**Levene's test for Equality of variance**	**t-test**	**Sig (2-tailed)**	**Mean difference**	**Standard Error difference**
Age	70.1/ 73.9	8.4/ 6.8	1.54/ .79	57-88/ 62-98	3.18, .08 equal	-1.98	.05*	-3.12	1.58
Schooling	10.8/ 13.2	4.01/ 3.8	.73/ .44	6-20/ 6-23	.09, .77 equal	-2.9	.005*	-2.41	.83
Emotional health (GDS)	3.6/ 1.17	3.31/ 1.13	.6/ .13	0-12/ 0-5	32.86, .000 sig diff.	3.93	.000*	2.43	.62

Physical functioning	61.8/ 72.87	27.71/ 20.59	5.06/ 2.38	15-100/ 15-100	7.42, .008 sig diff.	-1.97	.06	-11.03	5.59
Role physical	60/ 69.3	35.1/ 37.57	6.41/ 4.34	0-100/ 0-100	.77, .38 equal	1.17	.24	-9.33	7.98
Body pain	79.63/ 71.67	21.97/ 23.41	4.01/ 2.7	22-100/ 22-100	.89, .35 equal	1.6	.11	7.97	4.97
General health	71.43/ 67.76	17.4/ 19.77	3.18/ 2.28	35-97/ 17-100	.36, .55 equal	.89	.38	3.67	4.13
Vitality	61.83/ 64.07	21.64/ 16.72	3.95/ 1.93	5-100/ 25-95	3.09, .08 equal	-.57	.57	-2.23	3.94
Social functioning	83.75/ 87.5	22.3/ 17.91	4.07/ 2.07	12.5-100/ 25-100	2.69, .1 equal	-.9	.37	-3.75	4.16

Role emotional	71.11/ 90.22	40.81/ 25.57	7.45/ 2.95	0-100/ 0-100	24.55, .000 sig diff.	-2.39	.02*	-19.11	8.01
Mental health	78.13/ 84.85	16.73/ 10.61	3.05/ 1.22	44-100/ 44-100	15.49, .000 sig diff.	-2.04	.05*	-6.72	3.29

* Statistically significant comparisons

Table 3

Comparison of non-depressed aphasic (n = 21; NDA) and depressed aphasic (n = 9; DA) participants' demographic data and SF-36 subscale scores.

Variable	**Mean** **NDA/ DA**	**Standard deviation** **NDA/ DA**	**Standard Error Mean** **NDA/ DA**	**Range** **NDA/ DA**	**Z**	**Asymp. Sig (2- tailed)**
Age	68.86/ 75.11	8.52/ 6.72	1.86/ 2.24	57-88/ 68-88	-2.02	.044*
Schooling	11.62/ 8.78	4.39/ 1.99	.96/ .66	6-20/ 6-11	-1.55	.122
Emotional health (GDS)	1.86/ 7.67	1.11/ 3.16	.24/ 1.05	0-4/ 5-12	-4.34	.000*
Physical functioning	73.81/ 33.89	18.63/ 25.71	4.07/ 8.57	25-100/ 15-90	-3.16	.002*
Role physical	71.43/ 33.33	27.71/ 37.5	6.05/ 12.5	25-100/ 0-100	-2.53	.011*
Body pain	82.67/ 72.56	19.15/ 27.42	4.18/ 9.14	41-100/ 22-100	-1.03	.302
General health	80.48/ 50.33	10.16/ 11.12	2.22/ 3.71	62-97/ 35-72	-4.07	.000*
Vitality	69.05/ 45	17.29/ 22.22	3.77/ 7.41	40-100/ 5-80	-2.87	.004*

Social functioning	91.07/ 66.67	13.19/ 29.97	2.88/ 9.99	62.5-100/ 12.5-100	-2.29	.022*
Role emotional	77.78/ 55.56	37.02/ 47.14	8.08/ 15.71	0-100/ 0-100	-1.45	.147
Mental health	82.48/ 68	16.07/ 14.28	3.51/ 4.76	44-100/ 48-88	-2.33	.02*

* Statistically significant comparisons

Table 4

Comparison of non-depressed aphasic (n = 21; NDA) and depressed aphasic (n = 9; DA) participants' relevant other variables.

Variable	**Mean** **NDA/ DA**	**Standard deviation** **NDA/ DA**	**Standard Error Mean** **NDA/ DA**	**Range** **NDA/ DA**	**Z**	**Asymp. Sig (2- tailed)**
Time post onset (months)	44.38/ 33.56	28.32/ 16.76	6.18/ 5.59	10-108/ 13-66	-.66	.511
WAB AQ (max 100)	74.18/ 74.7	20.75/ 13.09	4.53/ 4.36	21.9-95.8/ 61-95.2	-.32	.751
WAB SponSpee (max 20)	15.1/ 14.89	4.57/ 3.26	.98/ 1.09	4-20/ 10-20	-.69	.493
WAB Comp (max 10)	8.49/ 8.49	1.35/ 1.25	.29/ .42	6.05-10/ 6.8-10	-.09	.928
WAB Rep (max 10)	6.78/ 7.24	3.12/ 2.29	.68/ .76	0-10/ 3.4-9.7	-.11	.91

WAB Naming (max 10)	6.75/ 6.72	2.64/ 1.89	.58/ .63	0-9.5/ 4.1-8.9	-.43	.667
CADL-2 (max 100)	76.95/ 65.11	13.39/ 21.33	2.92/ 7.11	37-95/ 31-89	-1.29	.197
Number of Communication activities (max 45)	28.9/ 28.22	7.11/ 6.08	1.56/ 2.03	16-42/ 20-36	-.27	.785
Number in Social network* (no maximum)	19.24/ 24.67	10.76/ 16.56	2.35/ 5.52	5-51/ 5-51	-.5	.618
Number of Social activities (max 20)	13.05/ 12.11	2.62/ 2.15	.57/ .72	9-18/ 8-15	-1.03	.304

Table 5

Comparison of non-depressed aphasic (N = 21; NDA) and non-depressed non-aphasic (n = 73; NDNA) participants' data.

Variable	**Mean**	**Standard deviation**	**Standard Error Mean**	**Range**	**Levene's test for Equality of variance**	**t-test**	**Sig (2-tailed)**	**Mean difference**	**Standard Error difference**
	NDA/ NDNA	**NDA/ NDNA**	**NDA/ NDNA**	**NDA/ NDNA**					
Age	68.86/ 73.68	8.52/ 6.79	1.86/ .8	57-88/ 62-98	2.55, .11 equal	-2.7	.008*	-4.83	1.79
Emotional health (GDS)	1.86/ 1.07	1.12/ .95	.24/ .11	0-4/ 0-3	.72, .4 equal	3.23	.002*	.8	.27

SF-36 General health	80.48/ 68.7	10.16/ 19.13	2.22/ 2.24	62-97/ 17-100	6.76, .01 sig diff.	3.74	.000*	11.78	3.15

* Statistically significant comparisons

Table 6

Six-way comparison of transformed SF-36 subscale data using current research (groups and subgroups) and ABS data.

	Current Study			ABS	Current Study	ABS	
SF-36 Subscale	**Aphasic Mean SD Range**	**Non-depressed aphasic Mean SD Range**	**Depressed aphasic Mean SD Range**	**1995 ABS data 'stroke' Mean only**	**Non-aphasic Mean SD Range**	**1995 ABS data 'no stroke' Mean only**	**Comment** Significance taken from calculations reported in Tables 2, 3 & 5; Other data eyeballed for comparisons
Sample Size	30	21	9	110	75	4,459	
Physical Functioning	**61.8** 27.71	**73.81** 18.63	**33.89** 25.71	**45.0**	**72.87** 20.59	**67.9**	Aphasic *almost* significantly lower than non-aphasic; depressed

	15-100	25-100	15-90		15-100		aphasic significantly lower than normal aphasic; depressed aphasic similar to ABS stroke
Role Physical	**60**	**71.43**	**33.3**	**29.7**	**69.3**	**66.1**	Depressed aphasic significantly lower than normal aphasic; depressed aphasic similar to ABS stroke
	35.1	27.71	37.5		37.57		
	0-100	25-100	0-100		0-100		
Body Pain	**79.63**	**82.67**	**72.56**	**54.0**	**71.67**	**69.2**	
	21.97	19.15	27.42		23.41		
	22-100	41-100	22-100		22-100		
General Health*	**71.43**	**80.48**	**50.33**	**43.9**	**67.76**	**64.7**	Depressed aphasic significantly lower than

	17.4	10.16	11.12		19.77		normal aphasic; normal aphasic significantly higher than 73 non-aphasic; depressed aphasic similar to ABS stroke
	35-97	62-97	35-72		17-100		
Vitality*	**61.83**	**69.05**	**45**	**46.2**	**64.07**	**61.6**	Depressed aphasic significantly lower than normal aphasic; depressed aphasic similar to ABS stroke
	21.64	17.29	22.22		16.72		
	5-100	40-100	5-80		25-95		
Social Functioning	**83.75**	**91.07**	**66.67**	**64.4**	**87.5**	**82.0**	Depressed aphasic significantly lower than normal aphasic; depressed aphasic similar to ABS stroke
	22.3	13.19	29.97		17.91		
	12.5-100	62.50-100	12.5-100		25-100		
Role Emotional	**71.11**	**77.78**	**55.56**	**60.5**	**90.22**	**77.6**	Aphasic significantly

							lower than non-aphasic;
	40.81	37.02	47.14		25.57		depressed aphasic
	0-100	0-100	0-100		0-100		similar to ABS stroke
Mental Health*	**78.13**	**82.48**	**68**	**66.3**	**84.85**	**76.7**	Aphasic significantly
							lower than non-aphasic;
	16.73	16.07	14.28		10.61		depressed aphasic
	44-100	44-100	48-88		44-100		significantly lower than
							normal aphasic;
							depressed aphasic
							similar to ABS stroke

* Subscales are bipolar, where 50 = no limitations or disability, and 100 indicates positive well-being/ health state.